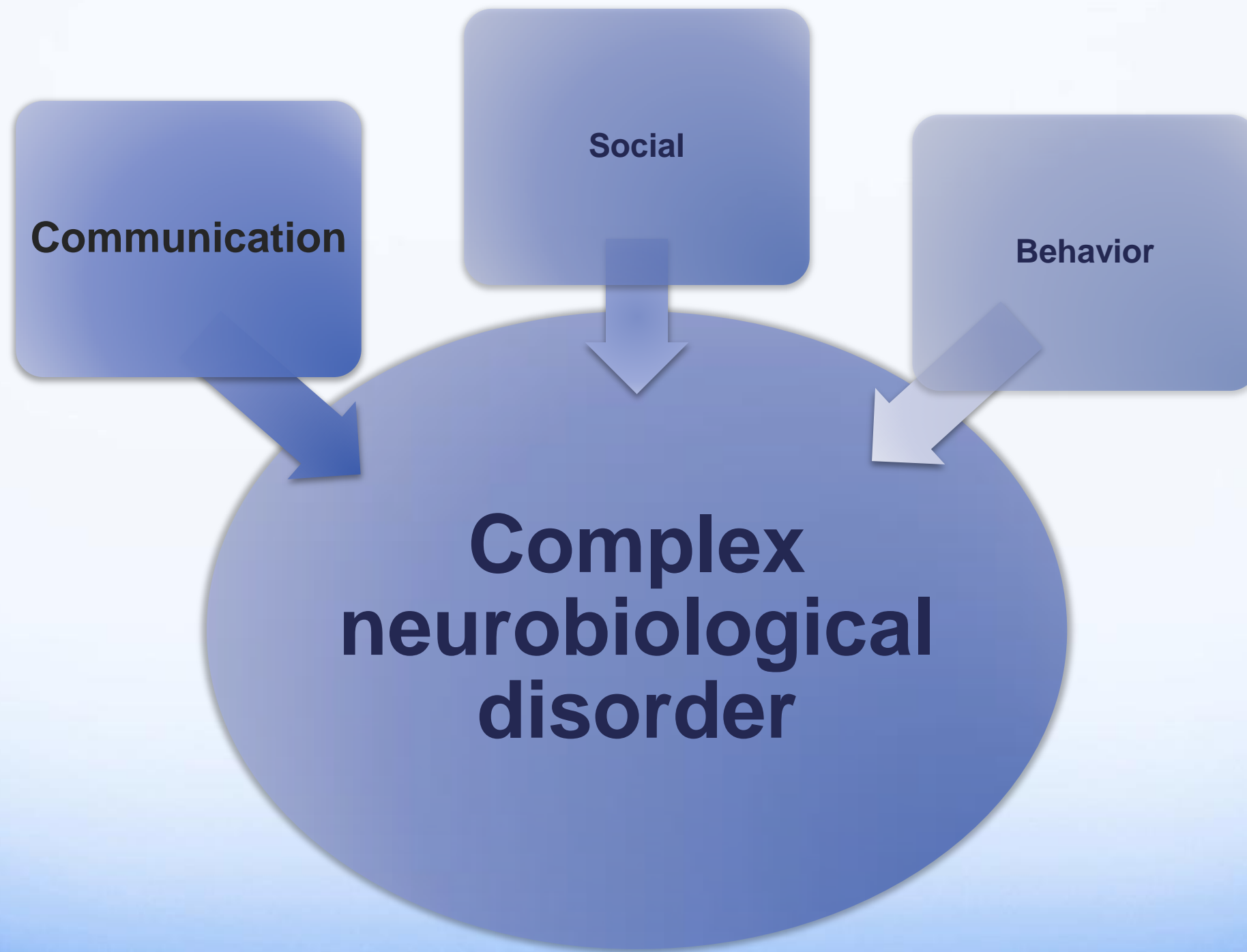




Providing a
Meaningful
Autism Benefit
for Individuals on
the Autism
Spectrum



What is Autism?



What is Autism?

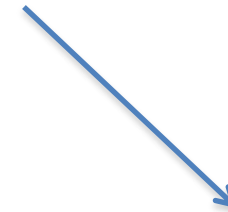
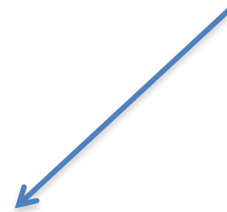
- Autism and autism spectrum disorder (ASD) are both general terms for a group of complex disorders of brain development.
- Autism affects a person's **communication** abilities and **social skills**, and often causes **repetitive patterns of behavior** and a narrow range of interests.
- Its symptoms range from mild to severe.



Severity is judged by amount of support one needs due to **social communication impairments** and **restricted, repetitive patterns of behavior**

Autism Spectrum Disorder

(The umbrella disorder in the DSM-V)



Level 3

Requiring very substantial support

Severe impairments in functioning as a result of severe deficits.

Level 2

Requiring substantial support

Marked deficits in functioning even with support in place

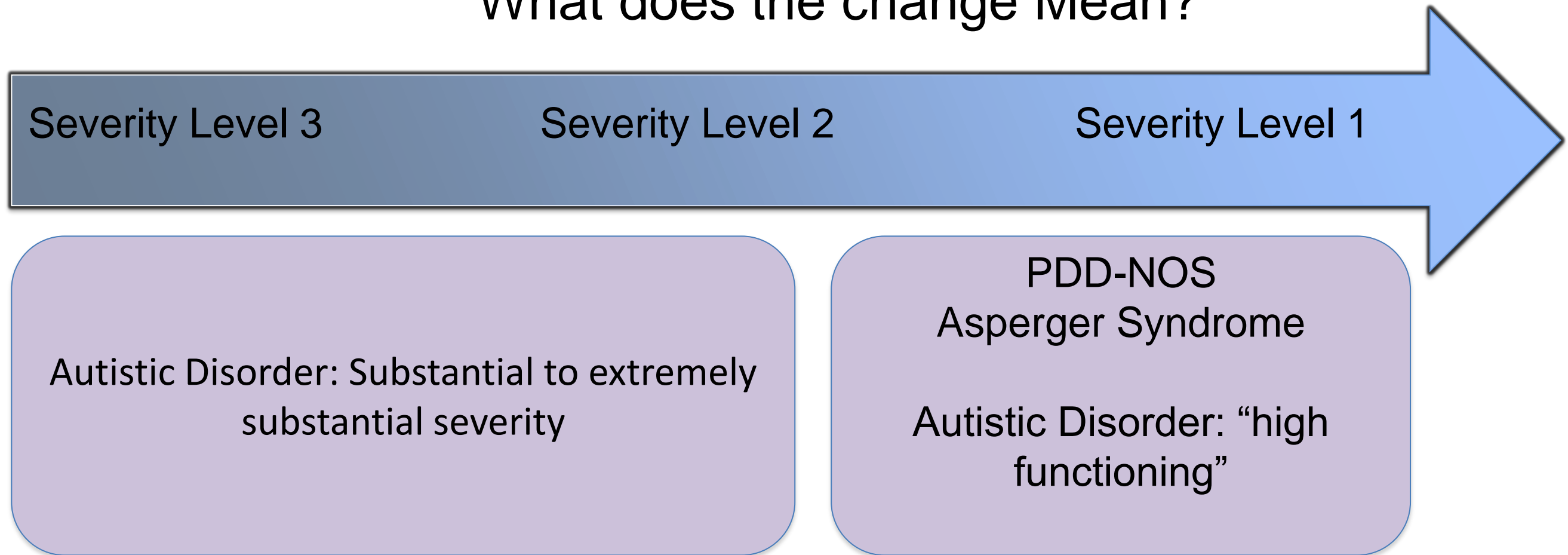
Level 1

Requiring support

Noticeable impairments in functioning

Autism Spectrum Disorder, DSM V

What does the change Mean?



“The sliding scale and single spectrum better reflects **symptoms presentation, time course and response to treatment**”-Department of Neurology, Boston Children’s Hospital

Diagnosing Autism

- The American Academy of Pediatrics recommends **screening** every child for autism at their 18 and 24 month checkups.
- Autism is **diagnosed** by a physician; usually by a developmental pediatrician, pediatric neurologist or team of developmental specialists.



Treatment

- Early diagnosis and treatment are critical to a positive outcome for individuals with an autism spectrum disorder (ASD)
- Treatment is prescribed by a licensed physician or licensed psychologist:
 - **Behavioral health treatment, including Applied Behavior Analysis (ABA) Therapy**
 - Speech, Occupational and Physical Therapy
 - Psychological, Psychiatric, and Pharmaceutical Care





June 20, 2012

Testimony of
Vera F. Tait MD, FAAP

On behalf of the
American Academy of Pediatrics

Before the
Subcommittee on Personnel,
Senate Armed Services Committee

American Academy of Pediatrics
601 13th Street NW, Suite 400
Tel: 800.336.5475 •

- “Optimizing medical care and therapy can have a positive impact on the habilitative progress and quality of life for the child. **Medically necessary treatments ameliorate or manage symptoms, improve functioning, and/or prevent deterioration.** Thus, in addition to routine preventive care and treatment of acute illnesses, children with ASDs also require management of sleep problems, obsessive behaviors, hygiene and self-care skills, eating a healthy diet, and limiting self-injurious behaviors.

- Effective medical care and treatment may also allow a child with ASD to benefit more optimally from therapeutic interventions. Therapeutic interventions, including behavioral strategies and habilitative therapies, are the cornerstones of care for ASDs. These interventions address communication, social skills, daily-living skills, play and leisure skills, academic achievement, and behavior.”



Applied Behavior Analysis (ABA)

- ABA is the most commonly prescribed **evidence-based** treatment for ASD
- Decades of research demonstrate the effectiveness of ABA therapy for autism
- Many insurers still deny coverage for ABA based on the assertion that ABA therapy is “experimental.” *This assertion is simply not supported by science*





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● **“An example of a demonstrated, effective treatment for ASD is Applied Behavior Analysis, or ABA.** ABA uses behavioral health principles to increase and maintain positive adaptive behavior and reduce negative behaviors or narrow the conditions under which they occur. ABA can teach new skills, and generalize them to new environments or situations. ABA focuses on the measurement and objective evaluation of observed behavior in the home, school, and community. “





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- “ASD is a medical/neurodevelopmental condition with behavioral symptoms that are directly addressed by applied behavior analysis methods. ABA has proved **effective in addressing the core symptoms of autism as well as developing skills and improving and enhancing functioning** in numerous areas that affect the health and well-being of people with ASD.”





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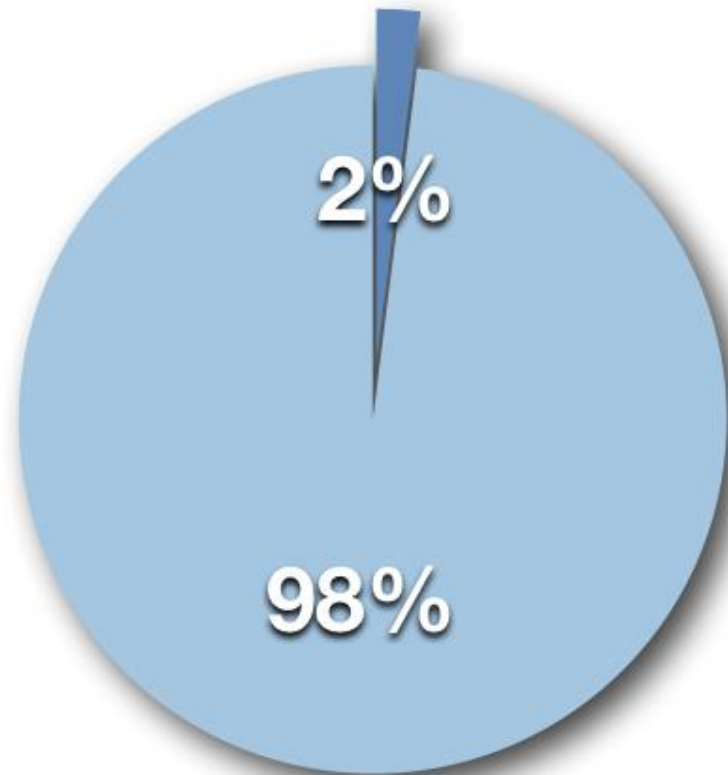
● “The effectiveness of ABA-based interventions in ASDs has been well documented through a long history of research in university and community settings. Children who receive early intensive behavioral treatment have been shown to make **substantial gains in cognition, language, academic performance, and adaptive behavior as well as some measures of social behavior**, and their outcomes have been significantly better than those of children in control groups.”



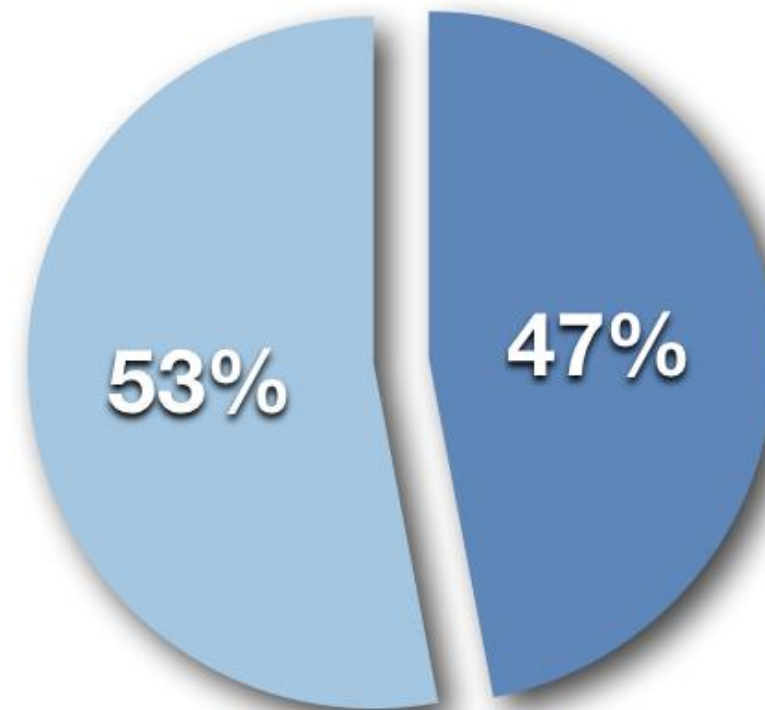
Outcome of Lovaas 1987 UCLA Study

Efficacy of ABA Therapy

Control Group



ABA Group

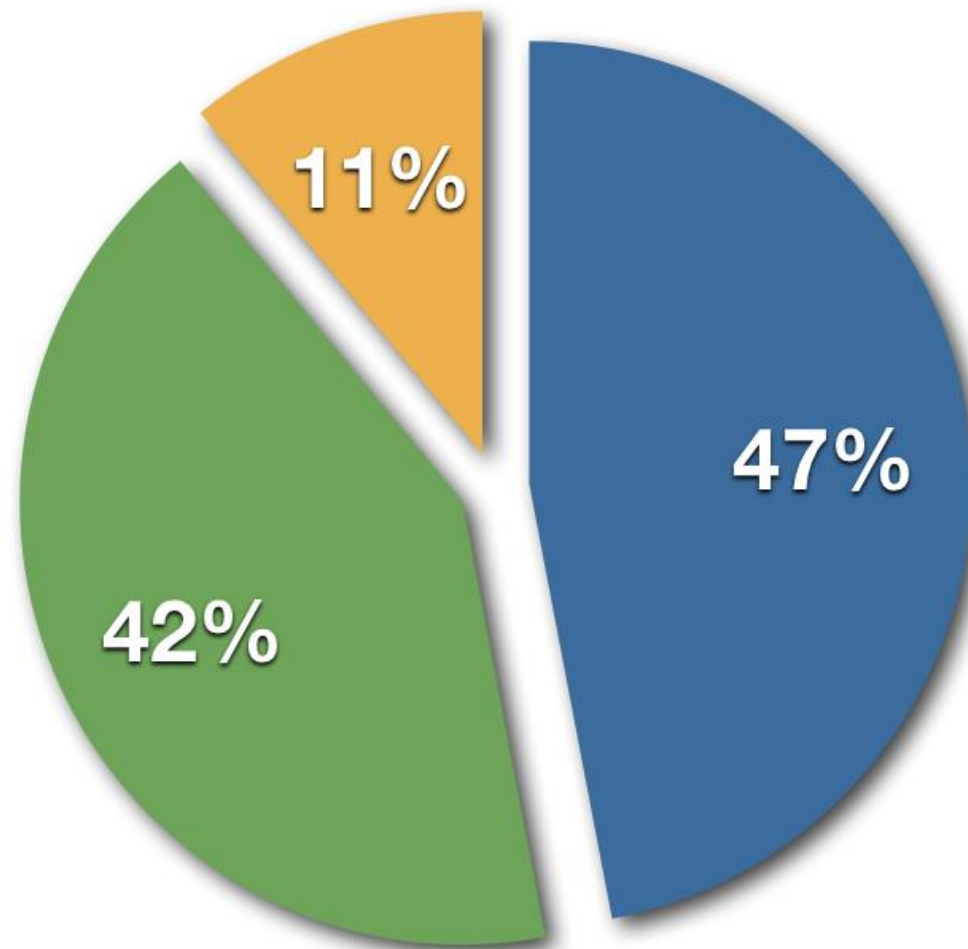


● Achieved Normal IQ

● Did Not Achieve Normal IQ

Outcome of Lovaas 1987 UCLA Study

Educational Placement for Group that Received ABA



- Mainstreamed with No Support
- Low-Intensity Special Education Placement (for language delay)
- High-Intensity Special Education Placement (for autism or intellectual disability)

ABA endorsements

United States Surgeon General (1999)

“Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”

The U.S. Office of Personnel Management (2012)

“The OPM Benefit Review Panel recently evaluated the status of Applied Behavior Analysis (ABA) for children with autism. Previously, ABA was considered to be an educational intervention and not covered under the FEHB Program. **The Panel concluded that there is now sufficient evidence to categorize ABA as medical therapy.** Accordingly, plans may propose benefit packages which include ABA.”



Facing Financial Reality

- According to a 2007 study conducted by the Harvard School of Public Health, it costs approximately \$3.2 million to take care of an autistic person over his or her lifetime.
- The Ganz 2007 Harvard study also found that caring for all people with autism over their lifetimes costs an estimated \$35 billion per year in direct and indirect costs.
- Estimated lifetime cost **savings** of providing appropriate treatment are \$1 million per child (Jacobsen et al, 1998)

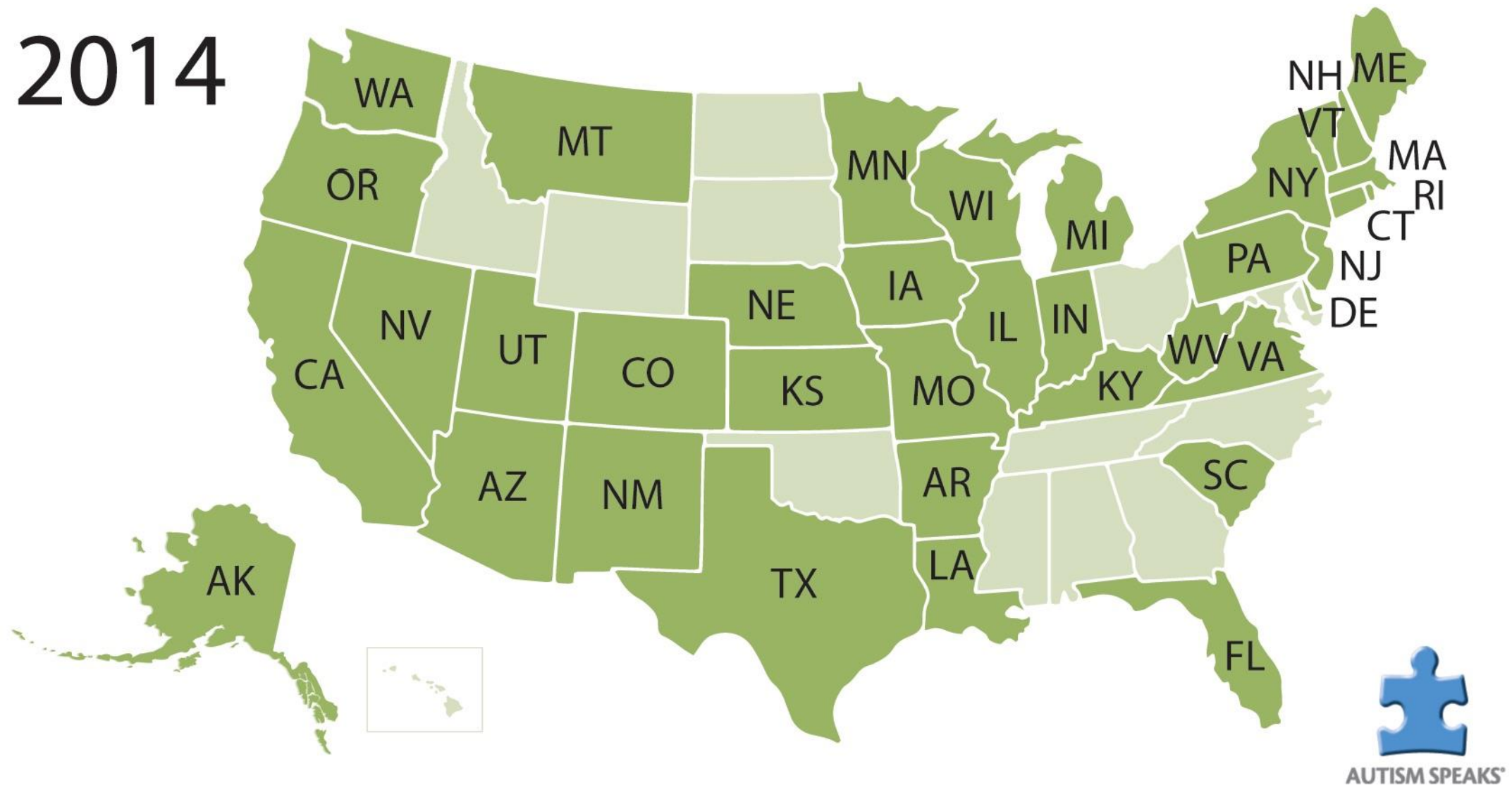


Autism Prevalence Since 2000



State Response

2014



38 states now require coverage of autism treatment,
including behavioral health treatments like applied
behavior analysis

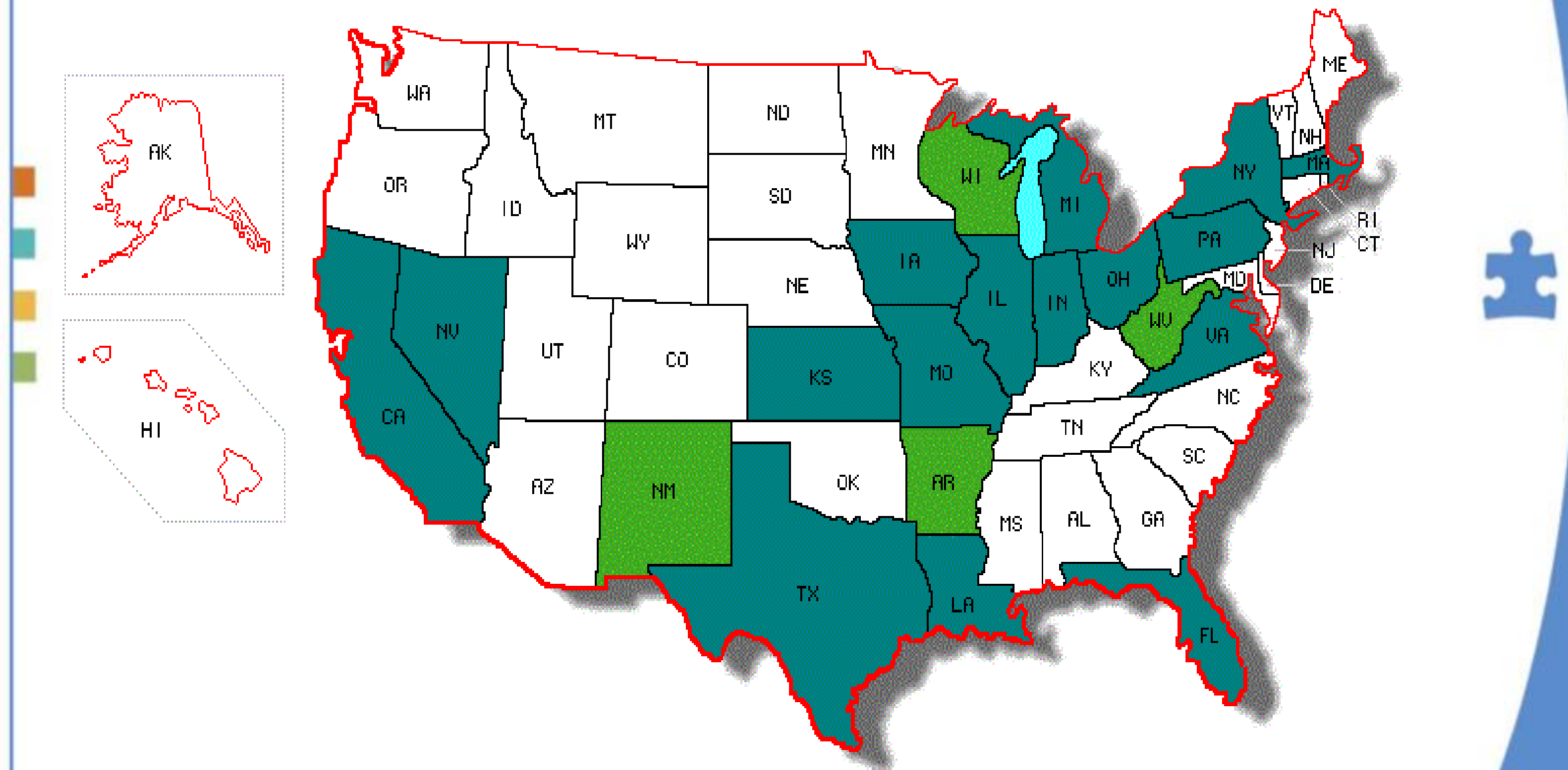
United States Department of Defense



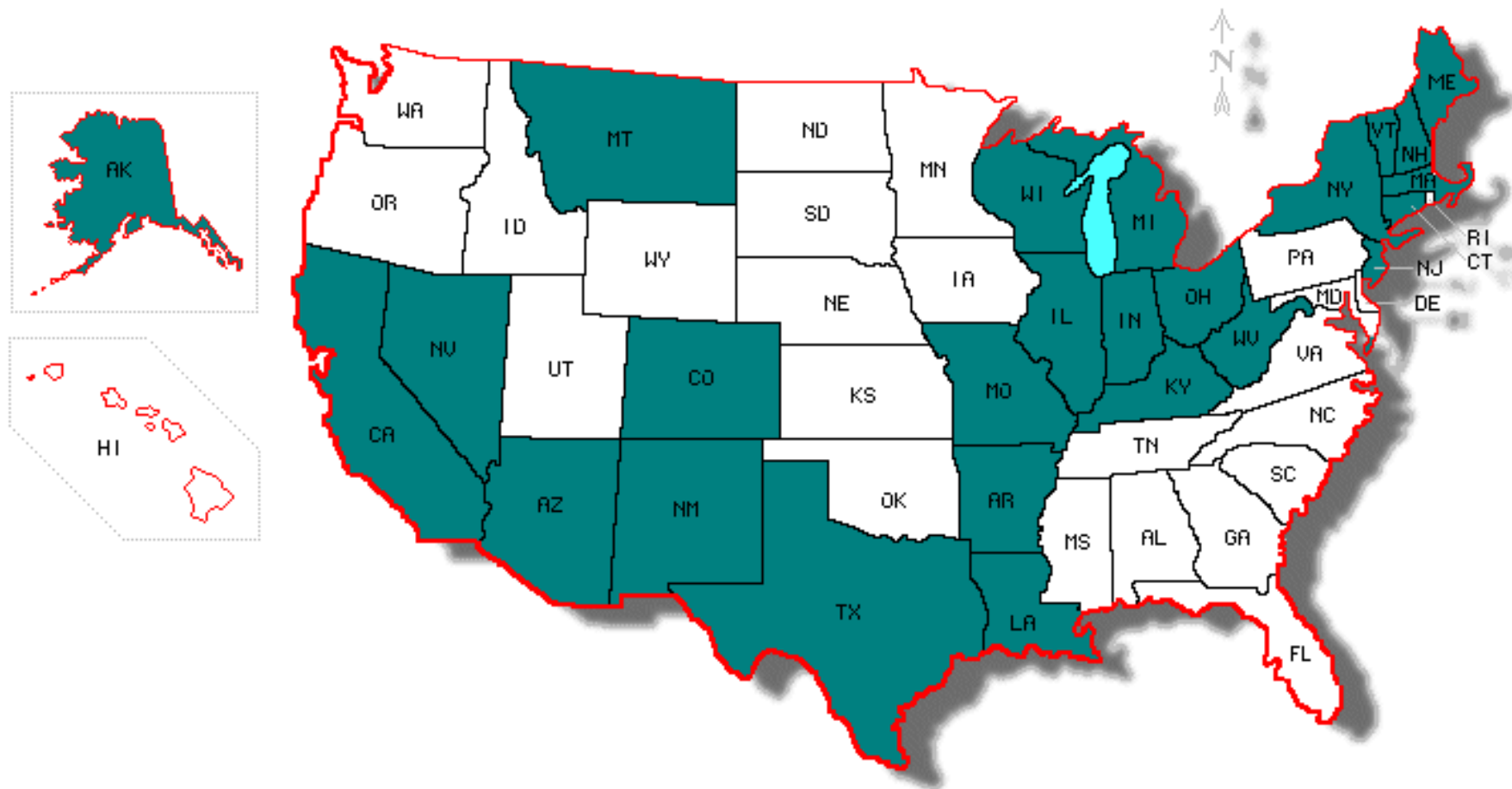
Tricare provides meaningful autism coverage for both active duty and retired military personnel, including behavioral health treatment like applied behavior analysis.



Federal Employee Health Plan 2014



ACA Marketplace Plans 2014



In States with Autism Insurance Reform...

- People who have never before been able to receive treatment are making remarkable progress.
- Providers have joined adequate networks of participating providers and negotiated satisfactory reimbursement rates.
- The impact on premiums has been negligible.



Cost of Coverage

If the out of pocket cost of treatment can be as high as \$60,000 per child per year, how can the reported claims data be so low?

- Autism is a **spectrum** and treatment is individualized based on the severity and individual needs of the affected individual.
- **Utilization** of benefits is not 100%

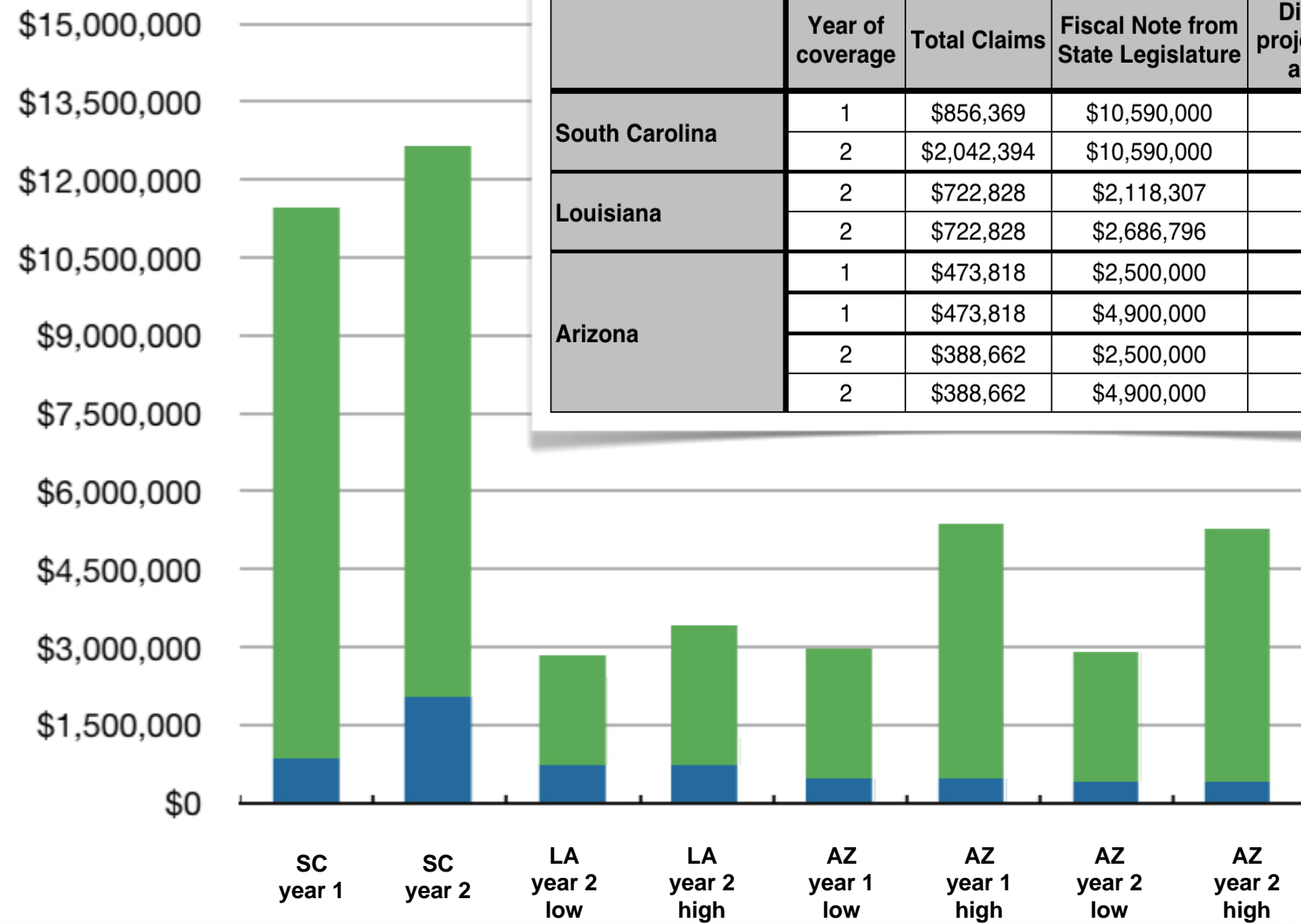
Utilization

- Of the estimated number of affected individuals, how many access treatment?
- **Disease Prevalence \neq Treated Prevalence**
- Based on claims data collected by Autism Speaks, estimated benefit utilization is **30-50%**. (*Minnesota providers report 20%.*)
- Contributing factors?
 - undiagnosed individuals
 - parent choice
 - higher functioning
 - socioeconomic status



Projected vs Actual Costs

■ Actual Cost
 ■ Fiscal Note from State Legislature



	Year of coverage	Total Claims	Fiscal Note from State Legislature	Difference in projected versus actual cost
South Carolina	1	\$856,369	\$10,590,000	1,237%
	2	\$2,042,394	\$10,590,000	519%
Louisiana	2	\$722,828	\$2,118,307	293%
	2	\$722,828	\$2,686,796	372%
Arizona	1	\$473,818	\$2,500,000	528%
	1	\$473,818	\$4,900,000	1,034%
	2	\$388,662	\$2,500,000	643%
	2	\$388,662	\$4,900,000	1,261%

The Cost of Autism Insurance Reform

	Year of coverage	Number of covered lives	Total Claims Paid	PMPM cost
South Carolina	2	397,757	\$2,042,394	\$0.43
Illinois	2	170,790	\$197,290	\$0.10
Louisiana	2	149,477	\$722,828	\$0.40
Florida	2	386,203	\$1,748,849	\$0.38
Arizona	2	130,000	\$388,662	\$0.25
Missouri	2	1,429,153	\$6,555,602	\$0.38
Kansas	2	99,465	\$309,216	\$0.26
	Average second year cost			\$0.31

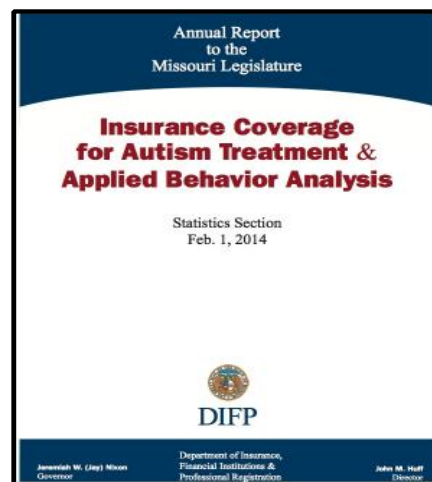
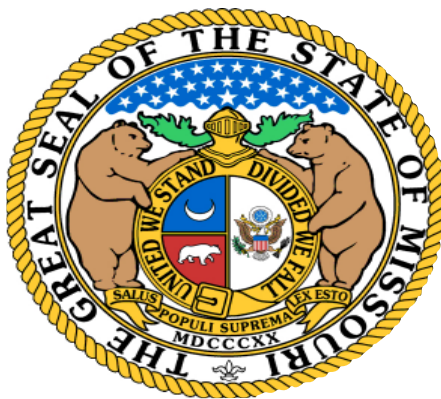
References: Data collected by Autism Speaks from State agencies responsible for administering State Employee Health Benefits Programs (2011); Missouri Department of Insurance, Financial Institutions and Professional Registration (2012); and the Kansas Department of Health and Environment (2012)

The Cost of Autism Insurance Reform

	Year of Coverage	Number of Covered Lives	Total Claims Paid	PMPM Cost
South Carolina	3	427,314	2,065,777	\$ 0.40
Illinois	3	208,466	416,741	\$ 0.17
Kansas	3	100,000	326,907	\$ 0.27
Missouri	3	1,443,680	8,289,917	\$ 0.48
New Jersey	3	597,104	4,482,066	\$ 0.63
Maine	3	29,637	67,384	\$ 0.19
Average Third Year Cost				\$ 0.46

References: Data collected by Autism Speaks from state agencies responsible for administering state Employee Health Benefits Programs (2011); Missouri Department of Insurance, Financial Institutions and Professional Registration (2012); and the Kansas Department of Health and Environment (2012)

Actual Claims Data Missouri



- Autism mandate implemented Jan 2011
- Terms
 - \$40,000/yr (cap only applies to ABA)*
 - until age 18*
- DIFP required to report claims costs annually

* Caps can be exceeded if deemed medically necessary

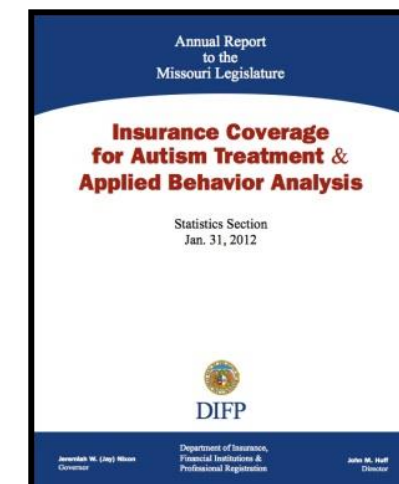
Source: Missouri Department of Insurance, Financial Institutions and Professional Registration

Missouri Department of Insurance Analysis of All Covered Plans 2011



YEAR ONE DATA

- Total claims paid = \$4,309,828
- Total covered lives = 17,332,763
- Unique claimants = 3,805
- PMPM cost = **25 ¢**



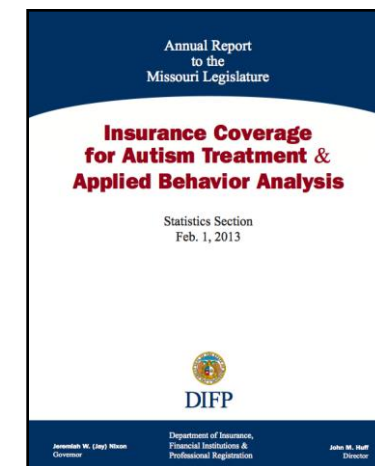
* Caps can be exceeded if deemed medically necessary

Missouri Department of Insurance Analysis of **All** Covered Plans 2012



YEAR TWO DATA

- Total claims paid = \$6,555,602
- Total covered lives** = 1,429,153
- Unique claimants = 2,508
- PMPM cost = **38 ¢**



* Caps can be exceeded if deemed medically necessary

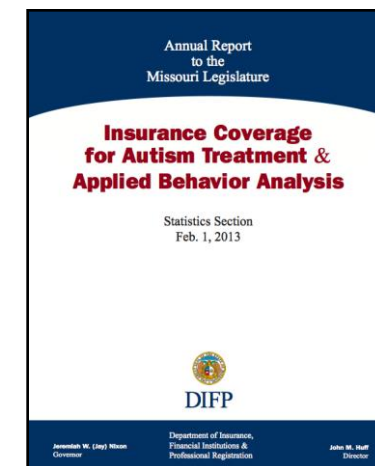
** Member months of policies with ASD coverage = 17,149,845

Missouri Department of Insurance Analysis of **All** Covered Plans 2013



YEAR THREE DATA

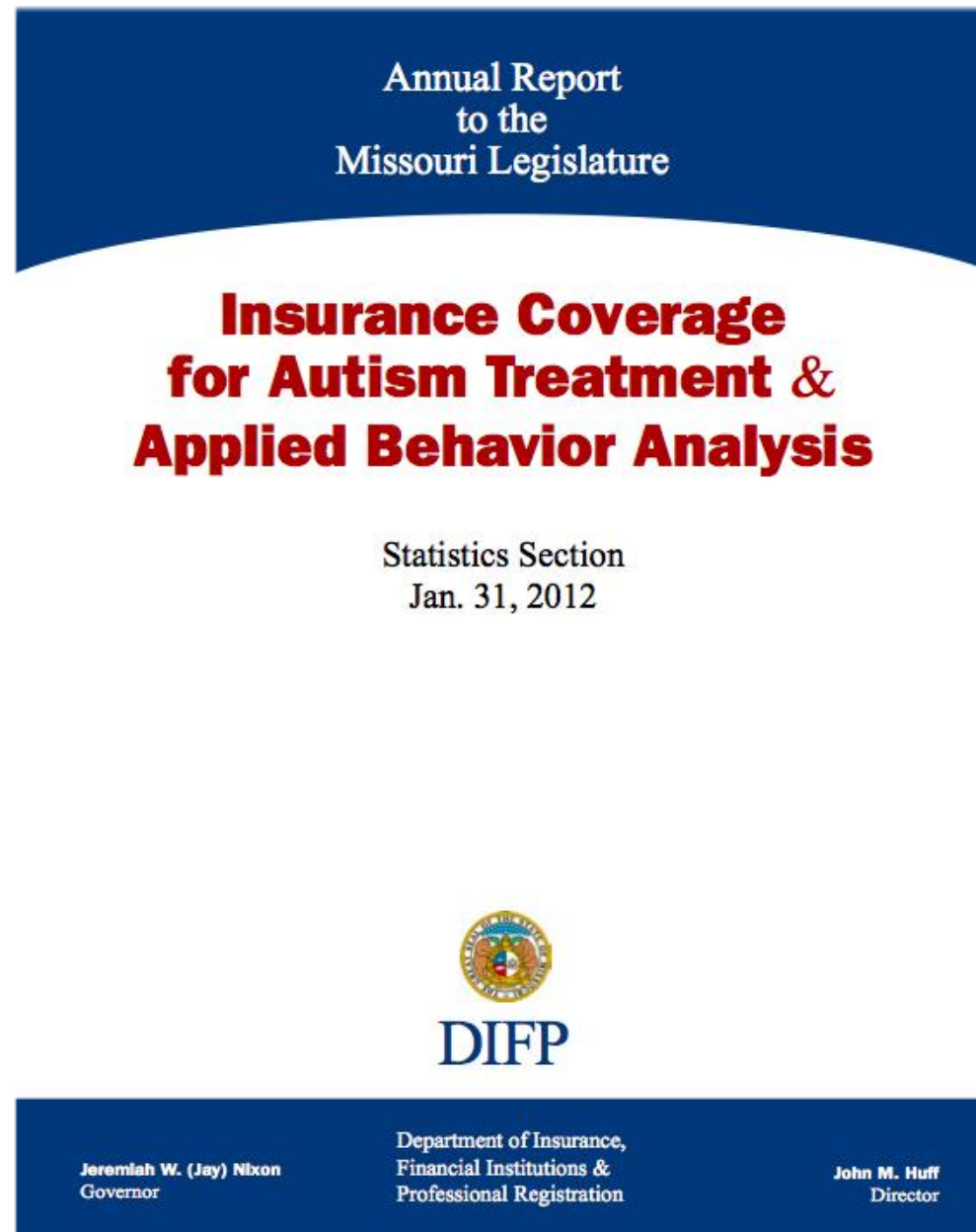
- Total claims paid = \$8,289,917
- Total covered lives** = 1,443,680
- PMPM cost = **48 ¢**



* Caps can be exceeded if deemed medically necessary

** Member months of policies with ASD coverage = 17,149,845

Effect on Premiums



- Claims incurred for treatment of ASD represent **0.9% of total claims**
- “While claims costs are expected to grow somewhat in the future, it seems very unlikely that costs for autism treatment will have an appreciable impact on insurance premiums.”



What is a Self-Funded Plan?

- Many companies (mostly large companies and some government positions) offer self funded health benefit plans.
- These benefit plans are called “self-funded” because the employer pays employee benefits from the employer’s own pocket and assumes the risks.
- Employers that self fund health benefit plans often hire third-party administrators (**TPAs**) to keep track of premiums, claims, and related paperwork.
- If the employee is in a self-funded plan, federal **ERISA** law preempts most state insurance regulation, including benefit reform.



NATIONAL SURVEY OF EMPLOYER-SPONSORED HEALTH PLANS

2013 SURVEY TABLES

Percentage of employers providing coverage for autism spectrum disorders:						
	Diagnostic services	Medication management	Speech, occ., physical therapies	Inpatient/outpatient treatment	Intensive behavioral therapies	Autism is not covered
Large employers	74%	63%	68%	56%	36%	18%
BY REGION						
West	74%	64%	70%	57%	41%	14%
Midwest	75	63	66	54	32	20
Northeast	74	61	68	59	39	20
South	74	65	69	56	32	18
BY INDUSTRY						
Manufacturing	79%	65%	69%	48%	29%	15%
Wholesale/Retail	70	51	61	55	26	22
Services	68	57	63	57	31	24
Transport/Communic/Utility	67	62	63	50	38	26
Health care	72	63	69	53	37	22
Financial services	87	72	78	76	55	8
Government	69	64	69	60	35	15
BY NUMBER OF EMPLOYEES						
500-999	69%	65%	64%	56%	31%	23%
1,000-4,999	79	64	72	57	39	16
5,000-9,999	70	52	65	47	30	20
10,000-19,999	78	57	70	62	40	13
20,000 or more	71	56	67	51	33	17

Mercer National Survey of Employer Sponsored Health Plans 2013

Self-Funded Plans that Provide Coverage for Autism Treatment

- Microsoft*
- Georgia Power
- Home Depot
- Arnold & Porter
- Symantec
- Cisco*
- Eli Lilly
- UTC
- Ohio State University
- Time Warner
- Cornell University
- MIT
- Blackbaud
- Lahey Clinic
- Partners Healthcare
- Deloitte*
- White Castle
- Wells Fargo
- Bank of America
- JP Morgan Chase
- University of Minnesota
- Progressive Group
- Intel
- DTE Energy
- Cerner
- Merck
- State Street Corporation
- Children's Mercy
- Capital One*
- Yahoo
- Rubbermaid
- Sisters of Mercy Health Systems
- Princeton University
- *and many more . . .*



What Should an Autism Benefit Look Like?

- Coverage should include
 - Behavioral Health Treatment, including Applied Behavior Analysis (ABA) Therapy
 - Speech Therapy, Occupational Therapy, and Physical Therapy
 - Psychological, Psychiatric, and Pharmaceutical Care
 - Diagnosis and Assessments
- No visit limits (other than restrictions prescribed by treating physician)



What Should an Autism Benefit Look Like?

- No denials on the basis that treatment is
 - Habilitative in nature
 - Educational in nature
 - Experimental in nature
- For Applied Behavior Analysis coverage, treatment must be provided or supervised by
 - a behavior analyst who is certified by the Behavior Analyst Certification Board®, or
 - a licensed psychologist so long as the services performed are commensurate with the psychologist's formal university training and supervised experience



Employee Retention

- “It meant so much to them that Microsoft cared about their employees, cared about their children, cared about their welfare, that Microsoft, as a company, was willing to do this. It made them feel really proud of their company. **That’s not the kind of company you leave.**” - Eric Brechner, **Microsoft** employee



(In an interview summarizing results of an employee survey relating to Microsoft's health benefits plan)

WALL STREET JOURNAL

- More Autism Help... As diagnoses of autism rise, a growing number of families are grappling with the worry and expense of finding treatment for children with the complex developmental disorder, autism. And many are pressing employers and legislators for help. (Wall Street Journal)

<http://online.wsj.com/article/SB10001424052748703867704576183022242647068.html>

- Bernie Marcus, Co-Founder Home Depot ... “The insurance lobbies obviously don't want to cover it and yet **we know the cost is only 32 cents per month per member. And they're fighting it tooth and nail. I put it into Home Depot years ago and I will tell you, it didn't break Home Depot.** “

- “There are powerful economic and social arguments for providing this benefit. We know that **if families have coverage for their children they will be better employees.**”



- - Ron Ashworth, Board Chair, **Sisters of Mercy Health Systems**



Cisco



- #90 on the 2012 **Fortune 100 Best Companies to Work For**
- 2007 **National Business Group on Health** Behavioral Health Award Winner for their autism benefit
 - In 2007, added autism benefit that included coverage for Applied Behavior Analysis (\$30,000/year; \$90,000/lifetime)
- In 2010, removed financial caps on coverage
- designates a key contact within each plan that would specifically focus on autism claims from Cisco employees.



Contact Information

Autism Speaks **State Government Affairs**

Lorri Unumb, Esq.

Vice President

lorri.unumb@autismspeaks.org

Judith Ursitti, CPA

Director

judith.ursitti@autismspeaks.org

Michael Wasmer, DVM, DACVIM

Associate Director

michael.wasmer@autismspeaks.org



About Autism Speaks

Autism Speaks is the world's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

Autism Votes is an Autism Speaks initiative; a comprehensive grassroots advocacy program, coordinating activist efforts in support of federal and state legislative initiatives.

For more information, please visit www.autismvotes.org and www.autismspeaks.org